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Psychosocial Health and Lifestyle Behaviors in Young Adults Receiving Renal Replacement Therapy Compared to the General Population: Findings From the SPEAK Study

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Rationale & Objective: Patients in late adolescence and early adulthood receiving renal replacement therapy (RRT) face disruption to normal activities, which affects well-being. We aimed to define psychosocial and lifestyle outcomes for young adults on RRT compared to the general population.

Study Design: We undertook a cross-sectional survey (the SPEAK [Surveying Patients Experiencing Young Adult Kidney Failure] Study) using validated measures and general population comparator data from the Health Survey for England and Avon Longitudinal Study of Parents and Children. Additional clinical information was obtained from the UK Renal Registry.

Setting & Participants: 16- to 30-year-olds receiving RRT.

Outcomes: Psychosocial health and lifestyle behaviors.

Analytical Approach: We compared outcomes between populations using age- and sex-adjusted regression models, weighted to account for response bias by sex, ethnicity, and socioeconomic status. Our findings were used to update recent meta-analyses.

Results: We recruited 976 young adults and 64% responded to the survey: 417 (71%) with kidney transplants and 173 (29%) on dialysis therapy. Compared to the general population, young adults on RRT were less likely to be in a relationship and have children and more likely to live in the family home, receive no income, and be unable to work due to health. They had poorer quality of life, worse well-being, and twice the likelihood of a psychological disturbance (OR, 2.7; 95% CI, 2.0-3.7; $P < 0.001$). They reported less smoking, alcohol and drug abuse, and crime. In a meta-analysis, our study showed the greatest differences in quality of life compared to the general population.

Limitations: Cross-sectional study design, meaning that we could not track the impact of treatment changes on the outcomes.

Conclusions: This study involving a large cohort of young adult transplant recipients and dialysis patients provides evidence of worse psychosocial outcomes but more positive lifestyle behaviors in young adults on RRT compared to the age-matched general population.

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Late adolescence and young adulthood is a neurodevelopmentally sensitive period during which important social milestones are crossed. However, this age group has been less well studied than childhood and early adolescence. Receipt of renal replacement therapy (RRT) affects the psychosocial health of individuals aged 16 to 30 years (defined here as "young adults"). A recent systematic review demonstrated reduced quality of life (QoL) compared to the general population, particularly for patients on dialysis therapy. Young adults on RRT were more likely to be unemployed despite the same likelihood of higher education and had less independence, being more likely to live at home and less likely to be in a relationship.[1] A thematic synthesis of qualitative studies exploring the perspectives of young adults on the psychosocial impact of kidney failure described themes of uncertainty and liminality, difference and the desire for normality, and thwarted or moderated dreams and ambitions.[2]

The clinical characteristics of young adults on RRT are not well described owing to international differences in transition and transfer arrangements. Existing evidence is limited and biased toward young adults who underwent transplantation in childhood. Young adults on dialysis therapy and those presenting directly to adult services are understudied. Most studies are small and single center, and few compared outcomes to the general population.[1] Although there has been focus on the transition of childhood-onset kidney failure to adult services, there has been less emphasis on wider young adult services, accommodating those presenting after adolescence. This is a vulnerable group, with evidence showing that 1 in 10 young adults starting RRT aged 11 to 30 years had died within 5 years. Compared with transplant recipients, young adults on dialysis therapy and not listed for transplantation were 18 times more likely to die within 5 years.[3] Although transplantation is the treatment of choice, young adults are a high-risk group for kidney transplant loss.[4,5]

The World Health Organization to defines health as "… a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity."[6 (p1)] Psychosocial well-being is important to patients and may provide insights into perceived lack of engagement with

health care services[7] and adherence to medications. We aimed to compare psychosocial well-being and lifestyle behaviors for a national cohort of young adults receiving RRT with equivalent general population data.

Methods

The SPEAK (Surveying Patients Experiencing Young Adult Kidney Failure) Study is a single cross-sectional online self-completion survey for 16- to 30-year-olds receiving RRT in United Kingdom renal units that was developed after an initial pilot. The survey comprised questions from validated health surveys (described next) with available comparable normative data. Additional scales and tools covering aspects of chronic disease were also included (reported separately[8]). The study was granted ethics approval by the Health Research Authority National Research Ethics Service Committee South West-Cornwall & Plymouth, reference 15/SW/0101.

Clinical Participants

Study inclusion criteria were: (1) 16 years and older and younger than 31 years and (2) receiving long-term RRT. We chose a wide age range because there is no consensus definition of young adulthood. Individuals were excluded if participation was expected to cause psychological distress or they were unable to complete the questionnaire with assistance. Participants were identified and contacted by their local renal units. All National Health Service trusts with an adult or pediatric renal unit (n = 74) took part in the study, yet 2 did not recruit any participants. Sites opened sequentially and recruited for 6 months, between 2015 and 2017. In 4 of 8 trusts with both an adult and pediatric renal unit, no recruitment took place in pediatrics. We aimed to recruit 1,000 young adults and estimated a survey response rate of 50%, giving 500 individuals for analysis. Assuming equal group sizes (eg, comparing by sex), this would give 90% power to detect a standardized difference (z score) of 0.29 ($\alpha = 0.05$) and a difference in proportions of 10% for an outcome with a prevalence of 10% to 50%.

Participants selected whether to access the survey by e-mail or a computer at their renal unit (when available). If no survey response was received, e-mail reminders were sent at 7 days, and at 14 days the renal unit checked whether the survey had been received and provided a further reminder.

Choice of Questions and Comparator Populations

Two different population-based studies (The Health Survey for England [HSE] and Avon Longitudinal Study of Parents and Children [ALSPAC]) were chosen to enable us to have a sufficient breadth of questions to cover all aspects of psychosocial well-being and lifestyle. The HSE is a series of annual surveys about the health of people living in England,[9] with addresses chosen at random. Selected questions (Item S1) were used from the 2012 survey regarding psychosocial health and lifestyle behavior outcomes and responses from age-matched participants (aged 16-30 years; n = 1,515). ALSPAC is a longitudinal birth cohort study (children of the 90s) that recruited 14,541 pregnant women, their partners, and offspring between 1991 and 1992 in the Bristol region of the United Kingdom.[10] The children of the mothers recruited to the study are currently in their early 20s. Lifestyle behavior outcomes were chosen from the data dictionary[11] regarding alcohol and drug use from young people aged 18 years and regarding crime from partners. Ethical approval for the study was obtained from the ALSPAC Ethics and Law Committee. The scales included

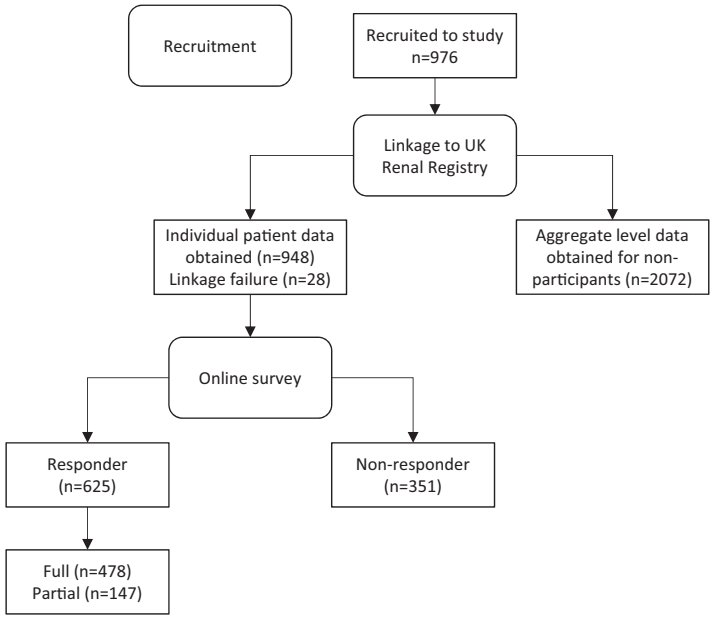

Figure 1. Flow chart shows study recruitment, survey response. and linkage to the UK Renal Registry.

Table 1. Clinical Characteristics and Comparison by Survey Response

Variable	Survey Responder (n = 625)	Nonresponder (n = 351)	Regression of Outcome by Survey Response (Responder vs Not)	
			OR/β (95% CI)	*P*
Male sex	51%	58%	0.75 (0.57-0.97)	0.03
Age, y	25 [21, 28]	25 [21, 28]		0.4
Age group: 16-<21, 21-<26, 26-<31 y	21%, 30%, 48%	21%, 33%, 46%	1.04 (0.81-1.32)	0.8
Country				
England	74%	87%	1.00 (reference)	
Scotland	6%	4%	1.60 (0.98-2.59)	0.06
Wales	10%	7%	5.07 (2.39-10.7)	<0.001
Northern Ireland	10%	2%	1.73 (0.92-3.25)	0.09
Ethnicity				
White	85%	81%	1.00 (reference)	
Asian	9%	13%	0.67 (0.44-1.01)	0.06
Black	4%	3%	1.08 (0.52-2.27)	0.8
Other	3%	2%	1.15 (0.49-2.69)	0.8
IMD quintile: 1 [least deprived],…, 5 [most deprived][a]	19%, 21%, 17%, 22%, 21%	16%, 17%, 15%, 21%, 30%	0.71 (0.56-0.90)	<0.001
Managed in adult center & aged <20 y	57% (total n = 101)	45% (total n = 51)	1.65 (0.84-3.22)	0.2
Managed in transplantation center	55%	54%	1.02 (0.79-1.34)	0.9
Managed in transition clinic center[b]	64%	62%	1.08 (0.83-1.42)	0.5
UKRR linked	97% (n = 609)	97% (n = 339)	1.35 (0.63-2.89)	0.4
Duration since RRT start, y[c]	6 [2, 11]	6 [2, 11]		0.8
Duration since RRT start: <5 y, ≥5 y[c]	41%, 56%	40%, 55%	0.99 (0.76-1.31)	0.9
Started in adult unit	59%	55%	1.19 (0.90-1.55)	0.2
Primary kidney disease[d]				
Glomerular diseases	27%	32%	0.83 (0.59-1.16)	0.3
Systemic diseases affecting the kidney	7%	6%	1.25 (0.70-2.23)	0.4
Familial/hereditary nephropathies	11%	8%	1.35 (0.82-2.23)	0.2
Tubulointerstitial diseases	31%	31%	1.00 (reference)	
Miscellaneous kidney disorders	18%	16%	1.12 (0.74-1.67)	0.6
Missing	6%	7%	—	
Time to RRT start from first nephrology review, d	745 [40, 1,984] (n = 431)	675 [62, 2,050] (n = 240)		0.6
Time to RRT start for those in pediatric services, d	667 [34, 1,923] (n = 396)	626 [60, 1,990] (n = 215)		0.7
Time to RRT start for those in adult service, d	1,048 [211, 3,441] (n = 35)	971 [487, 2,645] (n = 25)		0.9
Timeline data complete	97% (n = 590)	95% (n = 321)		
Starting modality				
Hemodialysis	37%	34%	1.60 (1.13-2.25)	<0.001
Peritoneal dialysis	39%	31%	1.88 (1.32-2.66)	<0.001
Transplant	21%	30%	1.00 (reference)	
Starting transplant type	(n = 125)	(n = 102)		
Live donor	46%	50%	1.00 (reference)	
Deceased donor	45%	43%	1.12 (0.65-1.93)	0.7
Unknown	9%	7%	1.38 (0.50-3.82)	0.5
Current modality				
Hemodialysis	24%	25%	0.96 (0.70-1.32)	0.8
Peritoneal dialysis	6%	5%	1.20 (0.64-2.25)	0.6
Transplant	71%	71%	1.00 (reference)	
Current transplant type	(n = 417)	(n = 227)		
Live donor	39%	54%	1.00 (reference)	
Deceased donor	52%	39%	0.95 (0.68-1.34)	0.8
Unknown	9%	7%	1.32 (0.70-2.51)	0.4

(Continued)

Table 1 (Cont'd). Clinical Characteristics and Comparison by Survey Response

Variable	Survey Responder (n = 625)	Nonresponder (n = 351)	Regression of Outcome by Survey Response (Responder vs Not)	
			OR/β (95% CI)	*P*
Ever had a transplant	82%	79%	1.13 (0.78-1.63)	0.5
Ever had a failed transplant	27% (total n = 502)	27% (total n = 268)	1.01 (0.73-1.42)	0.9
No. of transplants	1 ± 1	1 ± 1	1.05 (0.78-1.42)	0.8

Note: Participant interaction with the online survey that led to the generation of an identifiable survey record was counted as a response. Not all percentages may total 100 due to rounding. Data for continuous variables presented as median [interquartile range] when nonparametric or mean ± standard deviation.
Abbreviations: CI, confidence interval; OR, odds ratio; IMD, Index of Multiple Deprivation; RRT, renal replacement therapy; UKRR, UK Renal Registry.
[a]We used derived United Kingdom–wide IMD quintiles[26] using postcodes.
[b]As of September 2015,[27] with additional data obtained directly from renal units.
[c]If RRT start date was missing, the first timeline entry date was substituted.
[d]According to the 2012 European Renal Association–European Dialysis and Transplant Association coding system.[28]

in our questionnaire from these studies are displayed in Table S1.

Survey Software

Study data were collected and managed using Research Electronic Data Capture (REDCap) hosted at the University of Bristol.[12] REDCap is a secure web-based application designed to support data capture for research studies. It provided greater convenience to our participants than a paper survey by use of branching logic to deliver relevant questions based on preceding filter responses. Further, it avoided printing, postage, and data entry costs and reduced the risk for introducing data entry errors.

Clinical Data From the UK Renal Registry

The UK Renal Registry (UKRR) collects data for all RRT patients from all adult and pediatric renal centers in the United Kingdom.[13,14] The UKRR has been granted a section 251 exemption by the Health Research Authority. This exemption allows the use of identifiable patient information for certain audit and research activities without first asking the consent of each individual patient. All participants were asked for consent to access their detailed clinical characteristics from the UKRR database regardless of whether they completed the online survey or not (survey nonresponder). We also accessed anonymized summary-level data for study nonparticipants (those eligible for the study as of December 2015, but who did not give consent; n = 2,072) to enable comparison to the wider young adult population. This allowed us to examine and account for response bias and describe clinical aspects for young adults receiving RRT between participating survey responders, those who consented to access their data but did not complete the survey (participating survey nonresponders; individual data), and those for whom we had no contact (nonparticipants; aggregate data only).

Statistical Analysis

We undertook linear regression for continuous variables and logistic, ordered logistic, or multinomial logistic regression for binary, ordered categorical, and unordered categorical variables, respectively. Clinical characteristics were compared by survey response using regression. Characteristics were compared between survey responders and nonresponders/nonparticipants (Fig 1) combined using t test for continuous data and χ^2 test or Fisher exact test for categorical variables. Consequently, survey responses were weighted as the inverse of the sampling fraction for sex, ethnicity (white vs nonwhite), and socioeconomic status (SES) to be representative of prevalent young adults on RRT (Item S2). Thus, if some subgroups were under-represented in our survey compared to the general RRT population, they would be upweighted in the analysis to enhance the generalizability of our findings. The HSE team provide weights adjusting for selection, response, and population profile so that these were also used in the analyses. Outcomes were compared between young adults on RRT and the general population and between different patient groups (sex, modality, pediatric or adult starting unit, and duration) using age- and sex-adjusted regression models. For regression models, β coefficients are reported for continuous measures, and odds ratios (ORs), for categorical measures. The OR can be obtained by exponentiating the β coefficient. We tested for any difference in psychological aspects across age groups within SPEAK Study participants by including an interaction term in our analyses. We then performed a Wald test (because the likelihood ratio test cannot be used with survey weights) to assess the significance of the interaction.

We used our results to update recent meta-analyses of psychosocial health in young adults on RRT using methods previously described.[1] For selected sociodemographic and lifestyle outcomes, we used generalized linear models with Poisson regression and survey weights to estimate age- and sex-adjusted relative risk (RR). We undertook random-effects meta-analyses, given methodologic heterogeneity, to derive pooled RRs (95% confidence interval [CI], I^2 statistic, and 95% CI, t^2) using DerSimonian and Laird's method. For QoL, we used the EQ-5D tariff score. We performed random-effects meta-analysis using the Glass method (which standardizes using the reference group standard deviation) to pool standardized mean differences using the mean scale score, standard deviation, and sample

Table 2. Health and Anthropometric Aspects and Sociodemographics in UK Young Adults Receiving RRT, and Age- and Sex-Adjusted Regression Analyses Comparing to the Age-Matched General Population

Variable	N	Young Adults Receiving RRT	General Population	Adjusted External Comparison to the General Population[a]	
				OR/β (95% CI)	*P*
General health					
Self-rated health: very good, good/fair/bad, very bad	565	53%, 32%, 15%	88%, 10%, 3%	6.62 (5.21 to 8.41)	<0.001
Additional conditions lasting >1 y	564	41%	18%	3.16 (2.53 to 3.90)	<0.001
Had to reduce usual activities in last 2 wk	561	37%	12%	4.57 (3.63 to 5.81)	<0.001
Systolic BP, mm Hg[b]	460	130 ± 19	119 ± 12	10.6 (8.04 to 13.2)	<0.001
Diastolic BP, mm Hg[b]	442	79 ± 14	69 ± 10	10.2 (8.49 to 11.9)	<0.001
Ever had high BP	543	84%	5%	110.1 (68.5 to 176.9)	<0.001
Currently taking medication for high BP	245	81%	7%	29.3 (8.63 to 99.4)	<0.001
Ever had diabetes	541	5%	1%	8.67 (4.18 to 18.0)	<0.001
Anthropometry					
Self-reported height, m[c]	504	1.68 ± 0.12	1.71 ± 0.10	−0.05 (−0.06 to −0.04)	<0.001
Self-reported weight, kg	499	72.3 ± 21.2	71.5 ± 15.8	−1.43 (−3.77 to 0.91)	0.2
Body mass index, kg/m^2	488	25.6 ± 6.6	24.2 ± 4.7	0.92 (0.20 to 1.64)	0.01
Whether trying to change weight	524				
Not trying to change		35%	42%	1.00 (reference)	
Trying to lose weight		49%	45%	1.31 (1.03 to 1.67)	0.03
Trying to gain weight		16%	13%	1.65 (1.12 to 2.45)	0.01
Household and employment					
IMD quintile: 1 [least deprived],…, 5 [most deprived][d]	625	15%, 17%, 17%, 23%, 28%	15%, 18%, 20%, 22%, 25%	1.07 (0.68 to 1.67)	0.8
No. of people in household	578	3.4 ± 1.6	3.5 ± 1.6	0.10 (−0.10 to 0.30)	0.3
Married/living with partner	584	31%	33%	0.66 (0.51 to 0.86)	0.002
Natural children in household	569	14%	19%	0.56 (0.40 to 0.79)	0.001
Lives with parents or legal guardian	585	60%	47%	3.10 (2.32 to 4.14)	<0.001
If not living with parents or legal guardian:					
Accommodation tenure	231				
Renting		62%	74%	1.00 (reference)	
Owned outright		4%	2%	2.41 (0.98 to 5.99)	0.06
Mortgage		25%	23%	0.96 (0.66 to 1.40)	0.8
Live rent free		9%	1%	8.58 (2.77 to 26.31)	<0.001
Landlord	164				
Letting agency or individual private landlord		40%	69%	1.00 (reference)	
Local authority/council		27%	10%	5.16 (3.06 to 8.58)	<0.001
Housing association/cooperative/charitable trust/registered social landlord		13%	9%	2.92 (1.68 to 5.05)	<0.001
Other		2%	5%	0.72 (0.14 to 3.71)	0.7
Relative/friend		18%	7%	4.76 (2.53 to 8.94)	<0.001
Able to drive[e]	573	55%	—	—	—
Income sources (more than one may apply)					
Earnings	541	62%	83%	0.31 (0.23 to 0.40)	<0.001
Pensions, interest	541	5%	12%	0.41 (0.26 to 0.64)	<0.001
Jobseekers' Allowance, Employment Support Allowance, benefits	541	42%	51%	0.79 (0.59 to 1.05)	0.1
Credits	541	13%	29%	0.42 (0.29 to 0.60)	<0.001
Allowances	541	5%	9%	0.54 (0.32 to 0.89)	0.02
None	541	6%	1%	8.94 (2.34 to 34.1)	0.001
Household receives attendance/disability allowance	551	28%	9%	4.53 (3.00 to 6.82)	<0.001
Job status	569				
Employed		44%	52%	1.00 (reference)	
Full-time education		19%	30%	1.23 (0.87 to 1.77)	0.2
Unemployed		8%	8%	1.36 (0.97 to 1.93)	0.1

(Continued)

Table 2 (Cont'd). Health and Anthropometric Aspects and Sociodemographics in UK Young Adults Receiving RRT, and Age- and Sex-Adjusted Regression Analyses Comparing to the Age-Matched General Population

Variable	N	Young Adults Receiving RRT	General Population	Adjusted External Comparison to the General Population[a]	
				OR/β (95% CI)	*P*
Unable to work due to health		25%	2%	15.6 (9.97 to 24.5)	<0.001
Homemaker		5%	7%	0.90 (0.51 to 1.57)	0.7
Job type[f]	389				
Elementary occupations		15%	21%	1.00 (reference)	
Managers, directors, and senior officials		4%	3%	1.30 (0.64 to 2.66)	0.5
Professional occupations		13%	12%	1.17 (0.69 to 1.99)	0.6
Associate professional and technical occupations		10%	11%	0.93 (0.52 to 1.68)	0.8
Administrative and secretarial occupations		13%	12%	1.45 (0.84 to 2.46)	0.2
Skilled trades occupations		10%	11%	1.02 (0.61 to 1.68)	0.9
Caring, leisure, and other service occupations		11%	10%	1.63 (0.98 to 2.75)	0.06
Sales and customer service occupations		19%	16%	1.73 (1.09 to 2.75)	0.02
Process, plant, and machine operatives		4%	4%	0.86 (0.39 to 1.92)	0.7
Works full-time	403	57%	64%	0.50 (0.38 to 0.66)	<0.001
Self-employed	403	7%	6%	0.99 (0.61 to 1.63)	0.9
Education, qualifications, ethnicity, religion					
Age finished school	571				
Not yet finished		16%	29%	0.86 (0.52 to 1.43)	0.6
<16 y		18%	19%	1.00 (reference)	
17-18 y		32%	21%	1.67 (1.21 to 2.27)	0.002
≥19 y		34%	30%	1.13 (0.76 to 1.67)	0.6
Higher education/degree	560	38%	33%	0.97 (0.76 to 1.25)	0.8
Has a religion	477	41%	48%	0.73 (0.51 to 1.07)	0.1

Note: Unless otherwise indicated, data are proportions weighted by sex, ethnicity, and IMD to be representative of prevalent UK young adults receiving RRT. Outcomes are binary unless otherwise stated. Not all percentages may total 100 due to rounding. Data for continuous variables presented as mean ± standard deviation. The law requires all young people in England to continue in education or training until at least their 18th birthday. Young people aged 16 or 17 may leave school if they enter training or an apprenticeship.

Abbreviations: BP, blood pressure; CI, confidence interval; HSE, Health Survey for England; IMD, Index of Multiple Deprivation; OR, odds ratio; RRT, renal replacement therapy.

[a]Outcomes compared to weighted HSE (2012).[9]

[b]BP obtained from UK Renal Registry.

[c]Height *z* score adjusted for age and sex of those presenting in childhood was −1.05.

[d]United Kingdom–wide IMD quintiles[26] are compared with English 2010 quintiles in HSE 2012 data. Quintile cut-points are similar, corresponding to IMD scores of 8.8, 14.6, 22.1, and 34.4 for the United Kingdom–wide quintiles compared with 8.5, 13.8, 21.4, and 34.2 for England.

[e]Question not asked in HSE 2012.

[f]Coded using the Standard Occupational Classification 2010 (SOC2010) Volume 2 coding index.[29]

size for patient and control groups stratified by modality. We used Stata, version 14 (StataCorp LLC).

Results

Survey Response

As shown in Figure 1, the survey response rate was 64% (625 responders of 976 study recruits). Of those linked to the UKRR with complete current modality data (n = 590), there were 417 (71%) patients with transplants and 173 (29%) on dialysis therapy. There were 2,072 young adults known to the UKRR fitting the inclusion criteria who did not participate, meaning that we surveyed 32% of the total population of young adults on RRT (976 consenting to receive a survey of 3,048 prevalent young adults), obtaining survey responses in 21% (625 responding of 3,048 potentially eligible). As shown in Tables 1 and S2, survey responders were statistically more likely to be female, be white, and have higher SES compared with both survey nonresponders and study nonparticipants. We therefore weighted survey responses by sex, ethnicity, and SES to account for survey response bias. Survey responders were less likely to be managed in larger centers and transplantation units. Survey responders with transplants had slightly lower estimated glomerular filtration rates (by 4 mL/min/1.73 m^2) than nonresponders and nonparticipants, although this is of uncertain clinical importance (Table S3).

Clinical Characteristics

As shown in Table S2, UK prevalent young adults on RRT were 58% male, were 75% white, and had a median age of 25 years. The most common primary kidney disease group (33%) was tubulointerstitial diseases (due to structural causes) followed by glomerular diseases (27%), and median time since RRT start was 6 years. More than half (56%) started RRT in adult services. As expected, most underwent transplantation (73%), and mean estimated glomerular

filtration rate was 62 mL/min/1.73 m^2. Very few young adults were currently managed with peritoneal dialysis (5%, compared to 23% using hemodialysis). Of study participants, a fifth started RRT within 90 days of the first nephrology review. Around 80% of young adults had received a transplant, with 27% having experienced transplant failure.

Aside from end-stage kidney disease, young adults on RRT were 3 times more likely to have additional conditions ($P < 0.001$) compared to the general population (Table 2, with more detail shown in Table S4). Self-reported additional conditions are shown in Table S5. Compared to the general population, young adults on RRT were far more likely to ever have had high blood pressure (BP; OR, 110.08; 95% CI, 68.49-176.91; $P < 0.001$) and be taking medication for this (OR, 29.30; 95% CI, 8.63-99.45; $P < 0.001$). Mean BP was 130/79 mm Hg, which was approximately 10 mm Hg higher for both systolic and diastolic BP measurements ($P < 0.001$; Table 2) than the general population. BPs of young adults on dialysis therapy were approximately 10/6 mm Hg higher (systolic BP, $P < 0.001$; diastolic BP, $P = 0.001$) than those who underwent transplantation.

Young adults on RRT were 5 cm (adjusted for age and sex) shorter than the general population ($P < 0.001$). The height z score adjusted for age and sex of those presenting in childhood was −1.05. Weight did not differ, and body mass index was increased by around 1 unit ($P = 0.01$). Young adults on RRT appeared dissatisfied with their weight, being approximately twice as likely to perceive themselves as "too heavy" ($P = 0.001$) or "too light" ($P < 0.001$) and were more likely to be trying to gain (OR, 1.65; 95% CI, 1.12-2.45; $P = 0.01$) or lose (OR, 1.31; 95% CI, 1.03-1.67; $P = 0.03$) weight.

Sociodemographics

Young adults on RRT were less likely to be married or have a partner (OR, 0.66; 95% CI, 0.51-0.86; $P = 0.002$) or have their own children (OR, 0.56; 95% CI, 0.40-0.79; $P = 0.001$); they were 3 times more likely to live in the family home ($P < 0.001$) compared to the age-matched general population (Table 2, with further detail in Table S4). In terms of employment, young adults on RRT were less likely to report receiving any form of income except Jobseekers' Allowance, Employment Support Allowance, and benefits (OR, 0.79; 95% CI, 0.59-1.05; $P = 0.1$) and 9 times more likely to report receiving no income ($P = 0.001$). They were 15 times more likely to report being unable to work due to health ($P < 0.001$); when considering only those receiving RRT, dialysis patients were more likely to report being unable than transplant recipients (OR, 6.78; 95% CI, 4.36-10.55; $P < 0.001$). In those employed, occupations were similar to the general population except for an increased odds for sales and customer service occupations compared with elementary occupations (OR, 1.73; 95% CI, 1.09-2.75; $P = 0.02$). However, young adults on RRT were half as likely to work full-time ($P < 0.001$); again, when considering only those receiving RRT, dialysis patients were less likely to work full-time than transplant recipients (OR, 0.59; 95% CI, 0.35-1.00; $P = 0.05$). Young adults on RRT did not differ in SES or ethnicity compared to the age-matched general population (compared to white as the reference group, ORs of 1.17 [95% CI, 0.61-2.25] for Asian [$P = 0.6$], 1.48 [95% CI, 0.73-2.97] for black [$P = 0.3$], and 1.68 [95% CI, 0.84-3.32] for mixed/other ethnicity [$P = 0.1$]). With respect to education, young adult RRT recipients were nearly twice as likely to be aged 17 to 18 years when they finished school rather than younger than 16 years ($P = 0.002$), but educational delay was not assessed. They had the same likelihood of having higher education or a degree ($P = 0.8$).

Psychological Health

Compared to the general population, young adults on RRT had poorer QoL (OR for "No problems" on EQ-5D, 0.16; 95% CI, 0.13-0.21; $P < 0.001$; Table 3). They had inferior mental well-being (Warwick-Edinburgh Mental Wellbeing Scale [WEMWBS] β, −4.80; 95% CI, −6.22 to −3.39; $P < 0.001$; ie, 5 points lower on the scale). Using a General Health Questionnaire (GHQ-12) cutoff of ≥4 to define probable psychological disturbance or mental ill health, young adults on RRT had twice the likelihood of psychological problems ($P < 0.001$). There were no statistical differences across age groups within study participants (interaction term Wald test $P = 0.3$ [for EQ-5D], 0.07 [for WEMWBS], and 0.2 [for GHQ-12]). All aspects were worse for patients on dialysis therapy. As shown in Tables 3 and S5, according to the GHQ-12, a total of 31% had a psychological disturbance, but only 17% reported that their mental health was affected by their condition.

Lifestyle

As shown in Table 4, young adults on RRT were less likely to smoke ($P < 0.001$) compared to the general population. They were less likely ever to have drunk alcohol (OR, 0.06; 95% CI, 0.04-0.11; $P < 0.001$), were 1.6 years older at first alcohol consumption, and were less likely to demonstrate hazardous and harmful alcohol use (OR, 0.24; 95% CI, 0.12-0.48; $P < 0.001$). They were less likely ever to have tried cannabis (OR, 0.22; 95% CI, 0.12-0.37; $P < 0.001$) or other street drugs (OR, 0.37; 95% CI, 0.18-0.77; $P = 0.008$), to have spent money on gambling in the last 12 months (OR, 0.38; 95% CI, 0.29-0.51; $P < 0.001$), or to have been in trouble with the law (OR, 0.38; 95% CI, 0.24-0.60; $P < 0.001$). Young adults on RRT were twice as likely to report never having had sex ($P = 0.001$) and to have had sex with both men and women ($P = 0.02$, but based on small numbers) compared to the general population.

Revised Meta-analyses

Table S6 displays revised meta-analysis effect estimates. Compared to the general population, young adults on RRT are twice as likely to be unemployed (9 studies) despite the same likelihood of higher education (4 studies; RR, 1.02;

Table 3. Self-reported Psychological Aspects in UK Young Adults Receiving RRT, and Age- and Sex-Adjusted Regression Analyses Comparing to the Age-Matched General Population

Variable	N	Young Adults Receiving RRT	General Population	Adjusted External Comparison to the General Population[a]	
				OR/β (95% CI)	*P*
EQ-5D-3L tariff[b]	538	0.80 [0.62, 1.00]	1.00 [0.85, 1.00]	0.16 (0.13 to 0.21)	<0.001
Mobility: levels 1 [no problems], 2 [some problems], 3 [severe problems]	542	67%, 32%, 1%	96%, 4%, 0%	11.2 (7.54 to 16.6)	<0.001
Self-care: levels 1, 2, 3	541	81%, 19%, 0%	99%, 1%, 0%	22.4 (11.8 to 42.5)	<0.001
Usual activities: levels 1, 2, 3	541	61%, 34%, 5%	94%, 6%, 0%	9.78 (7.24 to 13.2)	<0.001
Pain/discomfort: levels 1, 2, 3	541	56%, 40%, 4%	86%, 14%, 1%	4.85 (3.78 to 6.17)	<0.001
Anxiety/depression: levels 1, 2, 3	540	51%, 40%, 10%	83%, 15%, 2%	5.16 (4.06 to 6.62)	<0.001
GHQ-12 scale score ≥ 4[c]	527	31%	15%	2.73 (2.01 to 3.71)	<0.001
WEMWBS score	535	47.4 ± 11.5	52.2 ± 8.2	−4.80 (−6.22 to −3.39)	<0.001

Note: Unless otherwise indicated, data are proportions weighted by sex, ethnicity, and IMD to be representative of prevalent United Kingdom young adults receiving RRT. Outcomes are binary unless otherwise stated. Not all percentages may total 100 due to rounding. There was no evidence for a difference across age grouping in SPEAK participants (Wald test $P = 0.3$, 0.2 and 0.07 for EQ-5D-3L tariff, GHQ-12 and WEMWBS scales respectively for interaction between cases/controls and age group). Values for continuous variables given as median [interquartile range] or mean ± standard deviation.

Abbreviations: CI, confidence interval; GHQ-12, General Health Questionnaire; IMD, Index of Multiple Deprivation; OR, odds ratio; RRT, renal replacement therapy; SPEAK, Surveying Patients Experiencing Young Adult Kidney Failure; WEMWBS, Warwick-Edinburgh Mental Wellbeing Scale.

[a]Outcomes compared to weighted Health Survey for England (2012).[9] Normative individual level EQ-5D visual analogue scores were not available.

[b]Grouped in regression analyses as "No problems"/"Some problems" corresponding to a tariff of 1 or <1.

[c]Probable psychological disturbance or mental ill health.

95% CI, 0.81-1.28), less likely to be in a relationship (5 studies; RR, 0.74; 95% CI, 0.60-0.90), and more likely to live in the family home (3 studies; RR, 1.65; 95% CI, 1.43-1.91). They are more than twice as likely to abstain from alcohol (4 studies) and less likely to smoke (3 studies; RR, 0.62; 95% CI, 0.40-0.97). Figure 2 displays a forest plot indicating that QoL is lower than that of the general population for patients with transplants (10 studies; standardized mean difference, −0.48; 95% CI, −0.74 to −0.22), and further reduced for patients on dialysis therapy (8 studies; standardized mean difference, −1.16; 95% CI, −1.72 to −0.60). In both cases, the difference in QoL compared to the general population was largest for SPEAK Study participants.

Table S7 shows internal comparisons by sex, modality, adult/pediatric start, and duration.

Discussion

Compared with studies reported in a previous systematic review,[1] SPEAK is a comparatively large survey of young adults on RRT compared to the general population and provides both medical and psychosocial data. We found that young adults on RRT were less likely to be in a relationship and have their own children and more likely to live in the family home, receive no income, and be unable to work for health reasons. They had poorer QoL, inferior mental well-being, and twice the likelihood of having a psychological disturbance. However, young adults on RRT reported more positive lifestyle behaviors, with less tobacco, alcohol, and drug abuse, gambling, and crime. This suggests that established kidney failure in young adulthood is associated with impaired psychosocial health and positive lifestyle behaviors compared to the age-matched general population.

These findings build on past evidence that also noted impaired employment, independence, relationships, and QoL. It reinforces evidence of less antisocial behavior and substance use compared to the general population in young adults starting RRT in childhood.[15] SPEAK adds both important context and comparison between outcomes by treatment modality. Participants reported being unable to work rather than simply unemployed, and those working were more likely to work part-time. SPEAK allows a direct comparison of different modalities in the same study, as opposed to comparing across different studies. We found that young adults on dialysis therapy not only had worse QoL, but also poorer mental well-being and psychological health than young adults who were transplant recipients. It is likely that psychological problems are under-recognized because we identified more using the GHQ-12 screening questionnaire than those of which young adults on RRT were aware.

Our data confirm estimates from a previous evidence synthesis[1] and have enhanced their precision, particularly for alcohol abstinence and smoking status. The qualitative similarity of our data with systematic review data highlights the generalizability of these findings worldwide. Despite between-study heterogeneity remaining high, this study strengthens the evidence base and adds granularity. In meta-analysis, SPEAK gave the biggest differences for QoL based on the largest sample size and a representative group of young adults on RRT. It is possible that previous studies were more likely to undersample patients with worse QoL scores.

We can go some way to explaining our findings through insights gained from the patient voice.[16] Topics from a thematic synthesis of qualitative studies on the experiences of young adults on RRT included: (1) changes in physical

Table 4. Self-reported Lifestyle Behaviors in UK Young Adults Receiving RRT, and Age- and Sex-Adjusted Regression Analyses Comparing to the Age-Matched General Population

Variable	N	Young Adults Receiving RRT	General Population	Adjusted External Comparison to the General Population[a]	
				OR/β (95% CI)	*P*
Smoking Status					
Never smoked, ex-smoker, current smoker	470	71%, 17%, 12%	59%, 17%, 25%	0.48 (0.39-0.60)	<0.001
Alcohol[b]					
Ever had a whole alcoholic drink	480	76%	96%	0.06 (0.04 to 0.11)	<0.001
Age had first alcoholic drink, y	377	15.9 ± 2.2	14.1 ± 2.0	1.59 (1.19 to 1.98)	<0.001
UDIT scale	347				
Low risk for alcohol-related problems		75%	40%	1.00 (reference)	
Hazardous and harmful alcohol use		25%	60%	0.24 (0.12 to 0.48)	<0.001
Drug Use[b]					
Ever tried cannabis	444	38%	39%	0.22 (0.12 to 0.37)	<0.001
Age when first tried cannabis, y	165	17.2 ± 2.9	15.4 ± 1.7	0.80 (−0.22 to 1.81)	0.1
Used cannabis within the last 12 mo	168	28%	64%	0.64 (0.17 to 2.34)	0.5
CAST group: no, low, high addiction risk	47	43%, 23%, 34%	92%, 5%, 3%	2.18 (0.16 to 30.88)	0.5
Ever tried other street drugs[c]	472	20%	18%	0.37 (0.18 to 0.77)	0.008
Crime[d]					
Ever been in trouble with the law	474	11%	30%	0.38 (0.24 to 0.60)	<0.001
Ever convicted of an offence apart from speeding	473	2%	17%	0.13 (0.06 to 0.28)	<0.001
Ever committed a crime	474	34%	72%	0.29 (0.22 to 0.38)	<0.001
Regretted any actions	175	60%	83%	0.22 (0.15 to 0.34)	<0.001
Sex					
Sexual experiences	435				
Had sex with opposite sex only		70%	76%	1.00 (reference)	
Never had sex with women or men		23%	20%	2.05 (1.36 to 3.10)	0.001
Had sex with same sex only		2%	1%	1.54 (0.64 to 3.74)	0.3
Had sex with both men and women		4%	3%	1.80 (1.11 to 2.94)	0.02
Age first had sex with opposite sex, y	337	17.3 ± 2.7	16.8 ± 2.3	0.21 (−0.20 to 0.63)	0.3
Ever had sex with same sex	451	6%	4%	1.48 (0.97 to 2.25)	0.07
Sexual orientation	455				
Heterosexual		89%	95%	1.00 (reference)	
Gay or lesbian		3%	2%	1.43 (0.67 to 3.06)	0.4
Bisexual		3%	2%	2.89 (1.39 to 5.99)	0.005
Other		1%	1%	2.39 (0.73 to 7.77)	0.2
Prefer not to say		3%	1%	2.83 (1.21 to 6.62)	0.02
Gambling					
Spent money on gambling activities in last 12 mo	479	41%	59%	0.38 (0.29 to 0.51)	<0.001
DSM-IV problem gambler	194	5%	1%	4.66 (1.32 to 16.61)	0.02

Note: Unless otherwise indicated, data are proportions weighted by sex, ethnicity, and IMD to be representative of prevalent UK young adults receiving RRT. Outcomes are binary unless otherwise stated. Not all percentages may total 100 due to rounding. Values for continuous variables given as mean ± standard deviation.
Abbreviations: ALSPAC, Avon Longitudinal Study of Parents and Children; AUDIT, Alcohol Use Disorders Identification Test; CAST, Cannabis Abuse Screening Test; CI, confidence interval; *DSM-IV, Diagnostic and Statistical Manual of Mental Disorders*; IMD, Index of Multiple Deprivation; OR, odds ratio; RRT, renal replacement therapy.
[a]Outcomes compared to weighted Health Survey for England 2012[9] unless otherwise stated.
[b]Compared with responses to the Your Changing Life questionnaire from the ALSPAC[10] (children aged 18 years).
[c]Other street drugs include cocaine, crack, amphetamine type stimulants, inhalants, sedatives, hallucinogens, opioids, and other stimulants.
[d]Compared with responses to the Partner–About Me questionnaire from the ALSPAC[10] (partners, when children aged 12 years).

appearance/body image, (2) barriers to activity and participation, (3) educational disruption and underachievement, (4) moderated career ambitions and employment difficulties, and (5) social isolation and intimacy issues, with a global theme of uncertainty and liminality.[2] Body image issues and decreased social participation leading to social isolation are likely to affect relationships; uncertainty and liminality may deter young adults from committing to a relationship or starting a family. Our findings support concerns over body image, with young adults being more likely to want to change their weight.

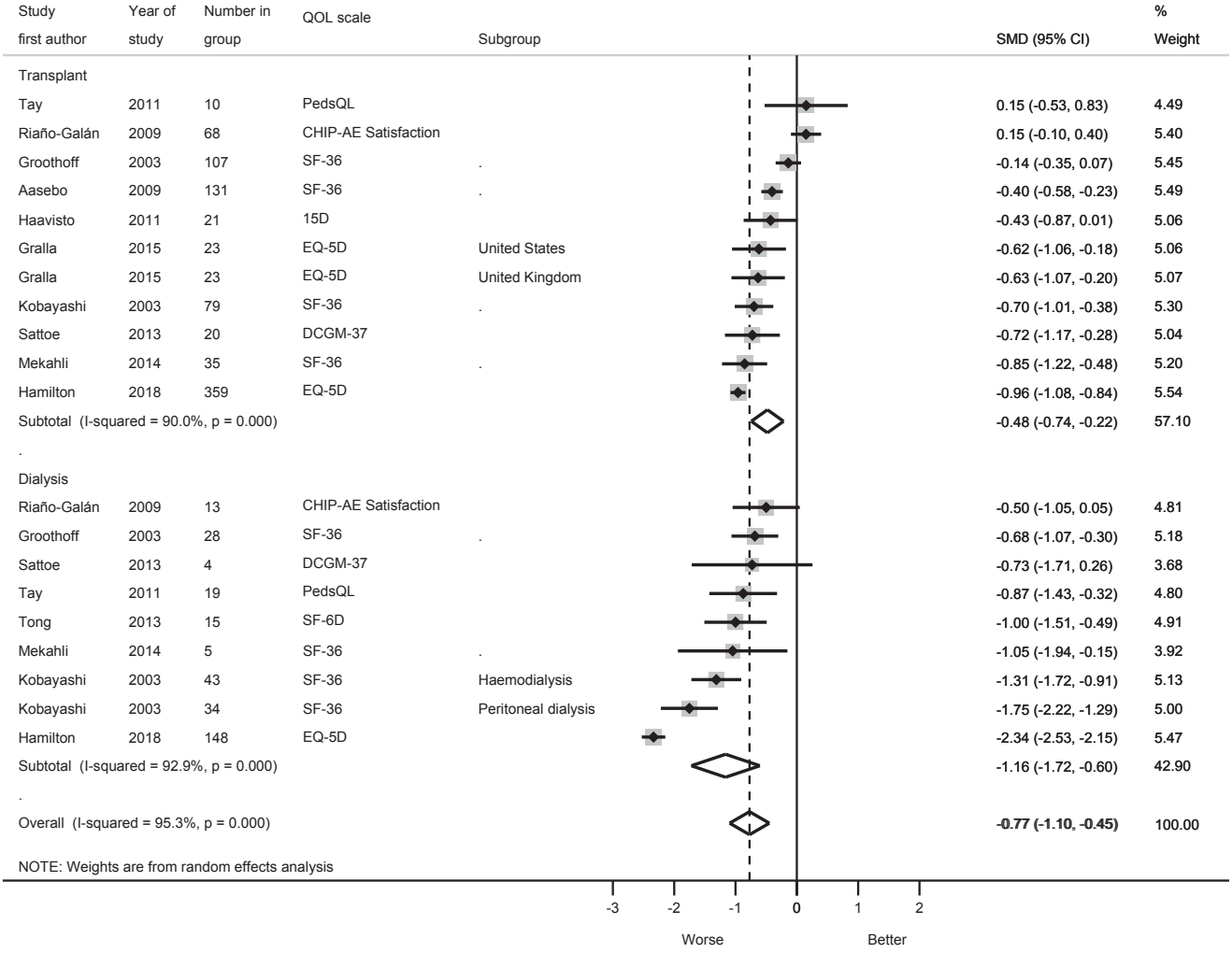

Figure 2. Forest plot of quality-of-life (QOL) scale scores show the contribution of Surveying Patients Experiencing Young Adult Kidney Failure (SPEAK) Study data to existing evidence. Abbreviations: 15D, 15-Dimension; CHIP-AE Satisfaction, Child Health and Illness Profile–Adolescent Edition; CI, confidence interval; DCGM-37, 37-item DISABKIDS Chronic Generic Module; EQ-5D, EuroQoL-5 Dimensions; PedsQL, Pediatric Quality of Life Inventory; SF-36, 36-Item Short Form Health Survey; SF-6D, 6-Dimension Short Form Health Survey; SMD, standardized mean difference.

Young adults often succeed in gaining significant academic qualifications despite a perception of educational underachievement, possibly due to health-related disruptions.[17] Being unable to work may necessitate protracted living in the family home, both diminishing independence and leading to impaired participation and social isolation. Physical health, social impacts, and life experiences are potential contributors to QoL and well-being,[18] perhaps explaining the worse QoL and psychological state in young adults on dialysis therapy.

Our findings with respect to EQ-5D utilities were comparable to those in a systematic review of utility-based QoL in adult chronic kidney disease treatments (young adult transplant recipient median of 0.85, compared to 0.82 [95% CI, 0.74-0.90]; young adult dialysis patient median of 0.66, compared to 0.70 [95% CI, 0.62-0.78]). In this review, age did not influence utility but was inconsistently reported.[19] Compared to a recent study of children on RRT showing similar QoL detriments by modality,[20] our meta-analytic evidence shows a clear modality difference for young adults. Furthermore, we found that 31% of young adults on RRT had psychological problems, similar to the overall meta-analytical prevalence of depression in adults with chronic kidney disease, reported at 34.0% (95% CI, 31.9%-36.2%).[21] Underdiagnosis of depression has been reported in older adult hemodialysis patients,[22] and systematic review estimates for the prevalence of depression are similar between adult transplantation, predialysis, and dialysis groups, albeit with greater precision for the latter.[21] However, importantly, self-report scales may overestimate depression when compared with clinical interview criteria, particularly for adults on dialysis therapy.[21] Physical activity shows promise in treating depression in adolescents and young adults[23] but may need special consideration in young adults because a third of SPEAK participants reported mobility problems.

Our study of clinical and psychosocial outcomes is strengthened by being a large cohort of young adult

transplant recipients and dialysis patients, with variation in modality and age at presentation, and by reporting normative data. Almost all UK renal centers recruited to the study and our survey had a similar response rate to a large previous study of young adults with kidney transplants.[24] Our data were linked to a national renal registry and we reduced survey response bias by weighting, thereby improving generalizability to the wider young adult population.

Our study has several important limitations. The design is cross-sectional rather than longitudinal, meaning that we could not track the impact of treatment changes on the outcomes. Most outcomes are based on self-report, which may be biased or overestimate outcomes such as depression. We had missing data both from nonresponders and nonparticipants, though summary data from the UKRR allowed us to quantify potential biases. Although we adjusted for some observed response bias, there may be other factors we could not adjust for (such as selection bias), so there may be residual bias. Multiple statistical associations were explored without adjustment of type 1 error; therefore, more modest associations, unless previously reported, should be treated with caution. We reported no difference in ethnic groups between young adults on RRT and HSE data. However, it should be noted that when comparing the ethnicity of prevalent young adults on RRT with census data from the Office for National Statistics, the former are statistically more likely to be Asian or black (ethnic proportions for those aged 16-<30 years living in England and Wales from the 2011 census from the Office for National Statistics[25] are 81% white, 11% Asian, 4% black, and 4% mixed/other, compared to 77%, 13%, 5%, and 4%, respectively, for prevalent young adults on RRT [$P < 0.001$, χ^2 test]). For a minority of our outcomes, we used comparator data from ALSPAC. Due to their status, ALSPAC participants may not be representative of the general population and this may reduce the observed differences. We did not capture all aspects of lifestyle and chose not to include questions on factors such as physical activity or diet because of their complexity and to reduce participant burden. For meta-analytic outcomes, there may be outcome reporting bias because the reasons that studies reported different outcomes are not completely clear.

In further work, we will examine aspects of chronic disease between patient groups and explore characteristics predictive of key outcomes, such as QoL. Future work should include qualitative research that will add further insights and the patient voice, as well as the development and testing of interventions aimed at improving modifiable psychosocial health.

In summary, this large national study highlights the importance of psychosocial problems in the young adult RRT population, despite healthier lifestyles, and their impact on QoL, social engagement, and employment. Clinicians and other health care professionals need a holistic approach to the management of these patients so that these issues are considered, as well as their renal health.

Supplementary Material

Item S1. Survey questions for outcomes defined in tables.

Item S2. Sampling fractions and derivation of survey weights.

Table S1. Summary of questionnaire scales.

Table S2. Clinical characteristics of prevalent UK young adults receiving RRT and comparison by study participation and survey response.

Table S3. Biochemical data of prevalent UK young adults receiving RRT and comparison by study participation and survey response.

Table S4. Health and anthropometric aspects and sociodemography in UK young adults receiving RRT, and age- and sex-adjusted regression analyses comparing to the age-matched general population.

Table S5. Self-reported conditions in addition to kidney disease in UK young adults receiving RRT, and regression analyses adjusted for age and sex comparing to the age-matched general population reporting a long-term condition.

Table S6. Updated pooled relative risk and standardized mean difference estimates from weighted meta-analysis relative to healthy controls, by study numbers and size, with heterogeneity statistics.

Table S7. Internal comparisons by sex, modality, starting unit, and duration of self-reported sociodemographic, general health and anthropometry and lifestyle in UK young adults receiving RRT.

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